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Original Article

Chinese family care patterns of childhood rheumatic diseases: A cluster analysis

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ABSTRACT

Objectives: The purpose is to distinguish family care (FC) patterns of childhood rheumatic diseases in Chinese families and to determine the predictors of FC patterns.
Methods: This secondary analysis contained two cross-section surveys with a convenient sample of totally 398 caregivers who have a child with rheumatic diseases from four pediatric hospitals. Caregivers were required to completed Family Management Measure questionnaire. Cluster analysis was used to distinguish patterns and multinomial logistic regression analysis was used to find predictors.
Results: Four patterns were identified: the normal-perspective and collaborative (28.4%), the effortless and contradictory (24.6%), the chaotic and strenuous (18.3%), and the confident and concerning (28.7%). Disease category ($\chi^2 = 21.23$, $P = 0.002$), geographic location ($\chi^2 = 8.41$, $P = 0.038$), maternal educational level ($\chi^2 = 12.69$, $P = 0.048$) and family monthly income ($\chi^2 = 33.21$, $P < 0.001$) predicted different patterns.
Conclusions: FC patterns were different among families. Disease-related and family-related factors were vital predictors to distinguish patterns consistent with the Family Management Style Framework. The result assisted that clinicians recognize FC patterns and predictors effectively to provide tailored advice in time.
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What is known?

- Childhood rheumatic diseases influence both individual and family life.
- Socio-economic status like parents' education and family income have significant association with family care of childhood chronic diseases.
- Parental involvements play an important role in managing childhood chronic diseases.

What is new?

- Four family care patterns in childhood rheumatic diseases were classified using Family Management Measure questionnaire.
- Contextual influences played crucial role in identifying care patterns.
- Family Management Style Framework was a reliable framework to help clinicians identify family care situation.

1. Introduction

Childhood rheumatic diseases (RDs) refer to systemic vascular inflammatory diseases of unknown origins that occur in children. The estimated prevalence of juvenile idiopathic arthritis (JIA) and systemic lupus erythematosus (SLE) was approximately 0.07–4.01 per 1000 children and 3.3–8.8 per 100,000 children respectively [1], while higher prevalence was reported in USA and Asian populations [2]. Recently, global researchers are paying more attention to children with rheumatic diseases related to disease burden or medication effects [3].

The symptoms of childhood RDs are prolonged and unexplained including fever, severe fatigue, musculoskeletal pain, activity and growth limitations, and nutritional status impairment [4,5]. RDs

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not only affect the physical health of children, but also influence psychological development including intelligence, arithmetic and emotion communication [6,7]. These children may require more complex care, utilize more hospital resources, and have more intricate parent-child relationship [8]. Children with a RD also continue to report disability and activity limitations into adulthood [9] and require extensive parental assistance [10]. Family caregivers have been regarded the vital role in children with chronic diseases [11]. Children suffering from chronic diseases usually fell behind the normal children in understanding and action because of the long-term hospitalization and absenteeism [12], so family caregivers spent more time and effort on dealing with the medical-related matters like observation the changes of disease in children, consultation on treatment strategies with clinicians [13,14]. Researchers have also reported that chronic diseases status can certainly change the family dynamics and adaptive coping, and parents can become physically and emotionally drained by the whole process [15,16]. The families experiencing childhood RDs undergo a profound life interruption and loss of family normalcy. Research indicated that family life difficulty was highly correlated with children's conditions [17].

Family care (FC) pattern refers to a relatively consistent typology of family response to a child's health care [18]. The family responses involve how the family define, manage and normalize their daily life when they have a child or adolescent undergoing a chronic condition [19]. The Family Management Measure (FaMM) is a widely used tool for measuring caregivers' perception of child care about how the family members can work together to incorporate children's disease issues and family daily life to promote clinical outcomes and family harmony, which derived from Family Management Style Framework (FMSF) developed by Professor Knalf [20]. FMSF emphasizes the basic of contextual influences like social network and so on, and interaction between person with condition and family members, which together influence the family's management behavior and ultimately determine care patterns. FaMM focuses on six dimensions in accordance with FMSF to reflect the different aspects of family responses and distil FC patterns [21].

According to the main component of contextual influences (social network, resource utilization, and interchanges with health providers), FC pattern can be characterized by child- and family-factors such as disease category, family income, geographic location and parental educational level in children with RDs. JIA and SLE were the most common rheumatic diseases that caused short-term or long-term malaise [22,23]. Due to the complexity and uncertainty of SLE and JIA in pediatric patients during the treatment [24,25], disease category played a crucial role in parental coping style. Besides, children with lower annual family incomes (<$50000 per year) displayed decreasing scores on physical function and quality of life [26]. It is noteworthy that families rarely deal with a single stressor, rather, they go through accumulative stressors and tension with the progression of the children's disease, especially for the family living in the rural areas with inadequate transportation, insufficient money and deficient medical resource [27], which increase more challenges in treatment. Furthermore, a meta-analysis indicated parents of children with chronic disease had higher educational level may adopt adaptive care pattern to care their child and led to better children's quality of life [28].

In recent years, the incidence of JIA and SLE in Chinese children has been increasing [29], while most of the pediatricians in rheumatology are currently in transformation from other areas, for example, nephrology, hematology or cardiology [30]. They lacked formally professional training to care for childhood rheumatic diseases, which indicated that there were more complex interrelation between contextual influences and FC patterns, and clinicians need to assess a series of challenges these families may meet and offer appropriate interventions to restrain the accumulation of stress and prevent family conflicts. Consistent with the report of World Health Organization (WHO), investing chronic diseases in low- and middle-income countries has generated major financial and health gains [31]. So it is meaningful to identify the patterns of FC among Chinese caregivers who had a child with RD and to explore what child- and family-factors were related to patterns.

2. Methods

2.1. Participants

This study used secondary analysis of data pool from two cross-sectional studies on FC of children with chronic diseases from four pediatric hospitals in Beijing and Shanghai. One was conducted from February 2008 to July 2011 examining impact of family management on family functioning, the other was conducted from June 2016 to June 2018 exploring the association among family management, transition readiness and quality of life [32,33]. Participants were primary caregivers of children with an RD. Inclusion criteria were as follows: (1) child was aged < 18 years; (2) the child was diagnosed with an RD such as SLE, JIA, and others; (3) the child and primary caregiver consented to the survey; and (4) the primary caregiver could speak and read Chinese. Exclusion criteria were: (1) child was in critical condition; (2) children were complication of multiple diseases.

2.2. Measures

2.2.1. Demographics

Demographic information was assessed by a self-designed questionnaire. Children's information included age, gender, disease category, disease duration. Family information obtained primary caregiver, family monthly income, geographic location, number of children, parental age, educational level and occupation.

2.2.2. Family Management Measure

The FC of children was assessed with the Chinese version of the FaMM, which was reported by caregivers, a 53-item questionnaire designed to measure 6 FC dimensions: children's daily life (CDL), condition management ability (CMA), condition management effort (CME), family life difficulty (FLD), view of condition impact (VCI), and parental mutuality (PM) [34]. We were approved to use it by the authors. It has acceptable reliability and validity. The FaMM is measured using Likert scale from 1 to 5, representing from totally disagree to totally agree. For the CDL, CMA, and PM subscales, higher scores indicate greater family management. For the CME, FLD, and VCI subscales, higher scores indicate worse family management. The content validity index (CVI) of the Chinese version the FaMM was 0.84. Meanwhile, this version was strong correlated with the Family Assessment Device and behavioral problem section in Child Behavior Checklist [34]. In one cross-sectional study, the internal consistency for CDL, CMA, CME, FLD, PM, and VCI were 0.74, 0.75, 0.62, 0.83, 0.74, and 0.86, respectively [32]. In another study, the alphas coefficients for the 6 subscales were 0.73, 0.72, 0.70, 0.84, 0.81, and 0.71, respectively [33].

2.3. Data collection

Eligible caregivers were recruited in the ward. Researchers informed the caregivers of the aim of the study and stated the study was voluntarily and the caregivers could refuse at any time. After researchers got the written informed consent from the caregivers, the caregivers were directed to the measures. Researchers were trained beforehand to provide the uniform instructions for

caregivers to finished the questionnaires. All data in the study were anonymous. Caregivers were compensated with a gift of ¥30 when they completed the whole questions.

2.4. Data analysis

The analyses were performed using SPSS 19.0 for Windows (SPSS Inc., Chicago, IL, USA). Descriptive statistics were reported using mean (standard deviation) or median (range) for continuous variables and number, percentage for categorical variables. Main data analysis comprised two steps.

First, a cluster analysis was performed to identify the FC patterns. Cluster analysis were initially performed using hierarchical cluster with the ward's linkage method in order to determine the possible cluster results according to the dendrogram and then K-mean cluster, an iterative partitioning method, was performed to confirm the best cluster result that each cluster must contain at least 5% in whole sample. Differences between subscales among clusters were examined using one-way analysis of variance (ANOVA) and the post-hoc tests applying the Bonferroni test.

Next, a multinomial logistic regression was performed to find the child- and family-variables predictors for each FC pattern. The likelihood ratio chi-square test (*Wald* χ^2) for model fitting information was used to determine the goodness of fit of each multinomial logistic regression model. The *B*-values, odds ratios (*OR*), 95% confidence intervals, *Wald* $\chi^2$and *P*-values were estimated and presented. A *P*-value <0.05 (two-tailed) was deemed statistically significant.

2.5. Ethical considerations

The ethical review board of Pecking Union Medical College approved and the Ethics Committee of the School of Nursing and Public Health, Shanghai Jiao Tong University approved the studies.

3. Results

3.1. Demographic characteristic

There were 398 primary caregivers in the analyses. Children's mean age was 11.51 ± 2.80 years. Median disease duration was 12 months, ranged from 0.23 to 144 months; 229 (57.5%) were girls. Of the type of diseases, 206 (51.8%) were diagnosed with JIA, 169 (42.5%) were diagnosed with SLE and 23 (5.7%) were diagnosed with other RDs. Regarding the families, 219 (55.0%) were mothers, whose mean age was 38.35 ± 4.76 years, 231 (58.0%) families lived in rural areas, 256 (64.3%) fathers and 225 (56.5%) mothers had a junior to high school education, 26 (6.5%) fathers and 139 (34.9%) mothers were unemployed, and 220 (55.3%) families had a monthly income ≤ 4,000 CNY. Detailed demographic data are shown in Table 1 [35].

Table 1
Characteristics of the 398 families.

Variables	Total (n = 398)
	Mean ± SD
Age (year)	11.51 ± 2.80
Paternal age (year)	40.26 ± 5.05
Maternal age (year)	38.35 ± 4.76
	Median(range)
Disease duration (month)	12 (0.23–144)
	n(%)
Sex	
Boy	169 (42.5)
Girl	229 (57.5)
Number of children	
One	168 (42.2)
More than one	230 (57.8)
Disease category	
JIA	206 (51.8)
SLE	169 (42.5)
other RDs	23 (5.7)
Primary caregiver	
Father	85 (21.4)
Mather	219 (55.0)
Grandparent	94 (23.6)
Geographic location	
Rural areas	231 (58.0)
Urban areas	167 (42.0)
Paternal educational level	
Less than junior school	81 (20.4)
Junior to high school	256 (64.3)
College degree or above	61 (15.3)
Maternal educational level	
Less than junior school	109 (27.4)
Junior to high school	225 (56.5)
College degree or above	64 (16.1)
Paternal occupation	
Blue-collar worker	225 (56.5)
White-collar worker	147 (37.0)
Unemployed	26 (6.5)
Maternal occupation	
Blue-collar worker	149 (37.5)
White-collar worker	110 (27.6)
Unemployed	139 (34.9)
Family monthly income (CNY)	
≤4,000	220 (55.3)
4,001–8,000	109 (27.4)
8,001–12,000	42 (10.6)
> 12,000	27 (6.7)

Note: *SD*, standard deviation; JIA, juvenile idiopathic arthritis; SLE, systemic lupus erythematosus.
For comparing with other studies and the parsimony of the regression model, we grouped parents' occupation into 3 categories: blue collar, white collar and unemployed according to the description of the nature of work in the United States Bureau of Labor Statistics [35].

3.2. Hierarchical cluster and K-means cluster

The hierarchical and K-means cluster analysis suggested that FC patterns could be grouped into 3, 4, or 5 clusters. An optimal cluster solution needs to consider clustering principle (statistically minimizes the within-group variability and maximizes the between-group variability), a sizable proportion of the sample in each cluster, and interpretability. We examined cluster solutions ranging from 3 to 5 clusters and compared the results of each *F*-value and $\eta^2$of a one-way ANOVA. The 4-cluster solution explained significantly more variance and was the best choice. Table 2 presents the mean scores of the 6 FaMM subscales, ranks, and the statistical results for the 4 clusters.

The aim of cluster analysis is to determine the commonality within group by measuring a given set of variables. So the label of each cluster should convey the commonality within group. We named the clusters based on the ranks of the variable means (6 FaMM) across the four clusters. The details were described below.

The normal-perspective and collaborative pattern (cluster 1) accounted for 28.4% (n = 113) of the caregivers. In this pattern, scores in CDL and PM ranked highest while scores in FLD and VCI ranked the lowest. Caregivers perceived their ill children were normal even though they had a RD, and they could organize the care tasks within the family system.

The effortless and contradictory pattern (cluster 2) accounted for 24.6% (n = 98) of the caregivers. In this pattern, score in CME ranked the lowest. Caregivers did not feel strenuous but still faced difficulties when caring for their ill children in the family.

The chaotic and strenuous pattern (cluster 3) accounted for 18.3% (n = 73) of the caregivers. In this pattern, scores in FLD and

Table 2
Mean scores of six FaMM scales for four clusters (*Mean* ± *SD*).

FaMM scales	Cluster 1 ($n = 113$)	Rank	Cluster 2 ($n = 98$)	Rank	Cluster 3 ($n = 73$)	Rank	Cluster 4 ($n = 114$)	Rank	η^2	F	P
CDL	4.13 ± 0.52	1[a]	2.92 ± 0.57	3[c]	2.51 ± 0.57	4[d]	3.69 ± 0.51	2[b]	0.56	169.96	<0.001
CMA	3.59 ± 0.45	2[a]	3.50 ± 0.50	3[a]	3.36 ± 0.60	4[b]	3.63 ± 0.54	1[a]	0.03	4.53	<0.001
PM	4.41 ± 0.56	1[a]	3.54 ± 0.51	3[c]	3.52 ± 0.66	4[c]	3.86 ± 0.67	2[b]	0.27	48.54	<0.001
FLD	2.39 ± 0.48	4[d]	2.95 ± 0.51	3[c]	3.70 ± 0.42	1[a]	3.50 ± 0.55	2[b]	0.51	138.46	<0.001
CME	3.20 ± 0.68	3[c]	3.02 ± 0.51	4[d]	4.24 ± 0.49	1[a]	4.04 ± 0.48	2[b]	0.46	112.49	<0.001
VCI	2.64 ± 0.43	4[c]	3.33 ± 0.47	3[b]	3.68 ± 0.46	2[a]	3.73 ± 0.55	1[a]	0.47	116.42	<0.001

Note: FaMM, Family Management Measure; SD, standard deviation; CDL, children's daily life; CMA, condition management ability; PM, parental mutuality; FLD, family life difficulty; CME, condition management effort; VCI, view of condition impact.
Values were ranked from the highest to the lowest.
Differences in post-hoc test represented the following order: a>b > c > d, $P < 0.05$.

CME ranked the highest, and scores in three positive subscales (CDL, CMA, and PM) ranked the lowest. Caregivers experienced a difficult family life and consumed vast energy to manage their children's condition. Meanwhile, caregivers were dissatisfied or in conflict with other family caregivers about care issues. They considered that their ill children were abnormal and had neither the competences nor the role to understand medical issues or deal with disease care.

The confident and concerning pattern (cluster 4) accounted for 28.7% ($n = 114$) of the caregivers. In this pattern, scores in CMA and VCI ranked the highest. Caregivers had adequate ability to care their children's condition; however, they were still aware of the impact of their children's disease on children and family.

3.3. Multinomial logistic regression analysis

We used multimonial logistic regression to predict membership of different FC clusters. The dependent variable was FC pattern (1 = The normal-perspective and collaborative pattern; 2 = The effortless and contradictory pattern; 3 = The chaotic and strenuous pattern; 4 = The confident and concerning pattern). The independent variables included children's and parents' age, disease category and duration, children's gender, parents' education and occupation, family location and monthly income. Table 3 displayed the results from the regression model with the 4 clusters regarded the cluster 1 (The normal-perspective and collaborative pattern) as the reference because this cluster represented an effective FC pattern, and previous researchers have revealed that appropriate family and child outcomes relates to an effective FC pattern [36], whereas the other 3 clusters represented some challenges in FC. There were four predictors obtained through the model based on the results of likelihood ratio chi-square test: disease category ($\chi^2 = 21.23$, $P = 0.002$), geographic location ($\chi^2 = 8.41$, $P = 0.038$), maternal educational level ($\chi^2 = 12.69$, $P = 0.048$), and family monthly income ($\chi^2 = 33.21$, $P < 0.001$).

Monthly income less than 12,000 Chinese yuan ($OR = 23.56$, 14.52, 19.55, respectively for monthly income "less than 4,000 CNY", "4,001–8,000 CNY", "8,001–12,000 CNY"), rheumatic diseases other than JIA ($OR = 0.10$) increased the likehood of being the effortless and contradictory pattern.

Living in the rural areas ($OR = 2.54$), monthly income less than 4000 Chinese yuan ($OR = 6.94$) were the significant predictors of being the chaotic and strenuous pattern.

Living in the rural areas ($OR = 1.85$), monthly income less than 8,000 CNY ($OR = 7.67$, 3.94, respectively for monthly income "less than 4,000 CNY", "4,001–8,000 CNY"), rheumatic diseases other than JIA and SLE ($OR = 0.04$, 0.06, respectively), the level of maternal education higher than high school ($OR = 0.16$, 0.37, respectively for "less than junior school" and "junior to high school") increased the likehood of being confident and concerning pattern.

4. Discussion

This was the first study to use cluster analysis to identify FC patterns among families having a child with RDs in China. We identified four patterns, and three scales (CDL, CME and FLD) played crucial roles in identifying the patterns after post-hoc comparison by significant differences across the scores of four clusters. Moreover, some variables related to child and family (disease category, geographic location, family monthly income and maternal educational level) were identified to predict FC patterns in our study.

The result of 4-FC patterns were similar to the 4-classes solution identified in the previous study with 575 parents from 414 American families of children who had various chronic diseases, in which the authors classified family management classes based on both mothers' and fathers' scores on 6 FaMM subscales. Both studies found a primarily positive and a primarily negative care pattern, and 2 moderate patterns focusing on different aspects of family care [37]. Another study conducted in China generated 5 patterns with 339 caregivers' scores on 6 FaMM subscales, whose children had chronic kidney diseases. Each type of family care patterns in their study reflected different focus and characteristics [38]. The agreement and disagreement of different patterns assists health care professionals to understand how caregivers incorporated disease care into family routines and caregivers' view of their illed child, their own care capabilities and family life. Understanding the FC patterns is important for subsequently interacting, supporting or intervening with these families.

CDL scores had the greatest variability among the 4 clusters and the only meaningful subscale among the three positive subscales, indicating that caregivers had diverse perceptions of what constitutes normalcy in children's daily lives [20], which impacts the expectations of care and care for children with RDs. Tong et al. [39] interviewed JIA patients and found that dislike to being distinctive, endeavor to be normalcy, and misapprehension were the main themes to describe how JIA influenced them. RDs involve multiple systems, which limit children's activities like running, jumping, and grasping, and renal dysfunction may occur because of the side effects from the medication for RDs [39]. Children with RDs undertaking more inactive daily life compared to healthy children were more socially isolated on account of school absence and lack of empathy by peers and teachers [40], and were at risk for poor quality of life and a strained parent-child relationship [41]. All of these were strongly interfered with the normal development of physical and psychological for children, and consequently affected the caregivers' perceptions of children's conditions. Our result reflects that clinicians should focus on caregivers' perceptions of children with RDs carefully and provide the strategies of

Table 3
Summary of Multinomial logistic regression for four clusters.

	B(SE)	*Wald* χ^2	*P*	95% CI *for OR*		
				Lower	*OR*	Upper
Cluster 2 vs Cluster 1						
Intercept	- 5.19(1.64)	10.00	0.002	–	–	–
Disease category						
JIA = 1	- 2.36(1.13)	4.36	0.037	0.01	0.10	0.87
JIA = 0	Base	–	–	–	–	–
SLE = 1	- 1.61(1.13)	2.02	0.155	0.02	0.20	1.84
SLE = 0	Base	–	–	–	–	–
Geographic location						
Rural areas	0.58(0.31)	3.54	0.060	0.98	1.79	3.28
Urban areas	Base	–	–	–	–	–
Family monthly income(CNY)						
≤4,000	3.16(1.07)	8.73	0.003	2.90	23.56	191.49
4,001–8,000	2.68(1.09)	6.03	0.014	1.72	14.52	122.77
8,001–12,000	2.97(1.13)	6.99	0.008	2.16	19.55	177.20
> 12,000	Base	–	–	–	–	–
Maternal educational level						
Less than junior school	- 0.25(0.66)	0.15	0.703	0.22	0.78	2.82
Junior to high school	0.15(0.55)	0.07	0.786	0.39	1.16	3.44
College degree or above	Base	–	–	–	–	–
Cluster 3 vs Cluster 1						
Intercept	- 3.93(1.50)	6.85	0.005	–	–	–
Disease category						
JIA = 1	- 2.07(1.20)	2.99	0.084	0.01	0.13	1.32
JIA = 0	Base	–	–	–	–	–
SLE = 1	- 1.82(1.21)	2.29	0.130	0.02	0.16	1.72
SLE = 0	Base	–	–	–	–	–
Geographic location						
Rural areas	0.93(0.34)	7.43	0.006	1.30	2.54	4.95
Urban areas	Base	–	–	–	–	–
Family monthly income(CNY)						
≤4,000	1.94(0.70)	7.74	0.005	1.77	6.94	27.16
4,001–8,000	1.18(0.74)	2.60	0.107	0.77	3.27	13.78
8,001–12,000	0.49(0.89)	0.30	0.583	0.28	1.63	9.36
> 12,000	Base	–	–	–	–	–
Maternal educational level						
Less than junior school	- 0.63(0.70)	0.81	0.368	0.14	0.53	2.10
Junior to high school	- 0.09(0.60)	0.03	0.874	0.28	0.91	2.92
College degree or above	Base	–	–	–	–	–
Cluster 4 vs Cluster 1						
Intercept	- 3.76(1.33)	7.994	0.005	–	–	–
Disease category						
JIA = 1	- 3.19 (1.08)	8.67	0.003	0.01	0.04	0.34
JIA = 0	Base	–	–	–	–	–
SLE = 1	- 2.68 (1.09)	6.47	0.011	0.01	0.06	0.53
SLE = 0	Base	–	–	–	–	–
Geographic location						
Rural areas	0.62 (0.31)	3.97	0.046	1.01	1.85	3.39
Urban areas	Base	–	–	–	–	–
Family monthly income (CNY)						
≤4,000	2.04 (0.64)	10.28	0.001	2.21	7.67	26.62
4,001–8,000	1.37 (0.66)	4.27	0.039	1.07	3.94	14.42
8,001–12,000	0.49(0.79)	0.39	0.533	0.35	1.64	7.72
> 12,000	Base	–	–	–	–	–
Maternal educational level						
Less than junior school	- 1.86 (0.62)	8.88	0.003	0.05	0.16	0.53
Junior to high school	- 1.00(0.51)	3.86	0.049	0.14	0.37	1.00
College degree or above	Base	–	–	–	–	–

Note: SE, standard error; CI, confidence interval; *OR*, odds ratios; JIA, juvenile idiopathic arthritis; SLE, systemic lupus erythematosus.
Cluster 1: The normal-perspective and collaborative pattern; Cluster 2: The effortless and contradictory pattern; Cluster 3: The chaotic and strenuous pattern; Cluster 4: The confident and concerning pattern.
$R^2 = 0.25$(Cox & Snell), 0.27(Nagelkerke). Model χ^2 (45) = 114.63, $P < 0.001$.

normalization and perspective changing [42].

CME and FLD were two significant negative subscales to determine the classification of the clusters. It is generally known that caregivers experience a mix feeling of uncertainty, anxiety, helpless and frustration regarding that they not only struggled with looking for treatment everywhere, controlling the symptoms, but also tending to reduce long-range functional disability and meanwhile maintaining normal life, which took them considerable time and effort [43]. Furthermore, RDs can remain active even into adulthood. Long-term use of corticosteroids was well known to compromise bone tissue, and increases the risk for bone fragility and fractures [39]. Simultaneously, the side effect of therapies also includes reductions in appetite [43], which lead to more problems in the process of growth and development for children and inevitably increased the burden and difficulty for caregivers. Because of physical limitations, children barely complete age-appropriate and

weight-bearing activities. Consequently, children became more dependent on the assistance of caregivers. In the past 20 years, insufficient social support still existed in seeking treatment and care information even in the large urban where always amassed a great deal of medical resources [16]. Structure interviews have been reported helpful in reducing the uncertainty and stress related to RDs and disease management for caregivers [44]. Therefore, this study suggests that clinicians should assist caregivers at developing expertise in managing their children's conditions consistently and forming an effective care model to minimize the negative influence on caregivers' normal life. In addition, clinicians have the responsibility to appeal for more social assistance to support families in need.

Our study identified that caregivers with children who were diagnosed with JIA or SLE were unlikely to be in cluster 4, which was characterized by confidence in managing the disease and concern about its consequence. One reason may be the complex care associated with JIA and SLE and frequent frustration that comes with the care. Children with JIA or SLE always experienced unpredictable episodes of active disease that were portrayed by fever, weight loss, fatigue, joint inflammation and pain, renal involvement, hematology or lymphatic abnormalities or functional limitations [45,46]. This unusual disease course demanded parents on multiple domains of functioning, such as searching for resources, planning long-journey for treatment, balancing the child's care and the entire household [16]. Parents struggled with the unknown, witnessed their child's suffering without ways to help, waited long-time for medical appointment. They felt drained physically and emotionally, and realized their limitation in care management [16]. Unequal access to health care services, constant adherence to complex treatment regimens, unprepared to transfer from pediatric to adult care were additional barriers for effective family care. This situation not only consumed parents' time and energy, but also affected the entire family [47]. For lack of security and stability, it is quite necessary for clinicians to have enough patience to provide clear information about how to detect the change of the condition and effective care to caregivers and children.

As is well know that maternal factors are of great importance to influence the children's care. Our study identifies that families with mothers with above high school also increase the likelihood of being in the cluster 4. Lower educational level always represents less health knowledge and lacking capacity to access the resource for disease management and has poor judgment to handle the various kinds of information [48]. On the contrary, mothers who have higher educational level can master the disease-related knowledge quickly, and have full confidence and ability in disease management. Highly educated mothers may be more conscious of fostering their children's sense of independence and had higher expectations for children, so that they were more worried about children's future regarding the influence of disease. Meanwhile, mothers with high educational level often take on the dual pressure of hectic work and child care. Our findings suggest that clinicians need to pay special attention to families with lower educated mothers and provide adequate resources about the disease knowledge and management instructions. As for highly educated mothers, clinicians were expected to provide guidance on effective disease management and mobilize the whole family members to take care of the children.

Socioeconomic factors and cultural factors affected children with RDs [49]. Our study identified that families who lived in rural areas, who had a monthly income less than 4000 Chinese yuan had a decreased likelihood of displaying an effective FC pattern. There is a paucity of literature about how low socioeconomic status families experience challenges such as meeting basic economic needs, family conflict, and parental stressors [50] leading to more severe children's disease conditions, less adherence to medication regimens, and poor health-related quality of life both in children and parents. Further, caregivers with a low SES usually have limited resources of disease regimens, knowledge of disease prognosis, and capacity of disease management [50]. They may prefer to acquire medical knowledge directly from clinicians rather than access this information through an electronic portal independently. So, it is vital that clinicians consider these factors when formulating care plans, research proposals, and policies to support the best results for these vulnerable families and prevent health disparities.

5. Limitation

Several limitations exist in the current study. First, the present sample was primarily hospitalized children and thus our results cannot be extended to the community caregivers. Further studies are needed to explore the FC patterns with diverse samples. Second, FaMM data were from one parent. This potentially limits support for validity without cross-parent or other main caregivers. The next step will be to examine and compare FaMM scores from both parents to fully understand FMS of a whole family. Third, our study only identified the FC patterns and predictors. Further study is expected to evaluate the strength of association between quality of life and FC patterns to improve the clinical efficacy. Finally, we were unable to consider that the FC pattern may change with time due to disease duration, the change of therapies or family caring skills. Therefore, a longitudinal approach to explore the changes in the pattern of FC is necessary.

6. Conclusion

This study identified four FC patterns and identified four factors relate to these patterns. This result is of immense clinical value and could guide clinicians to consider family care factors from caregivers' perspective to obtain a clearer picture of care experience. This domain-specific care experience assessment allows clinicians to determine best intervention components for specific families while considering diseases and socioeconomic diversity. Besides, our study extended the clinical utility of FaMM and FMSF in China.

Ethic approval

The ethical review board of Pecking Union Medical College approved and the Ethics Committee of the School of Nursing and Public Health, Shanghai Jiao Tong University approved the two studies involved in the present article.

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Authors' contribution

Conception and design: Ying Zhang, Jiali Ma; Acquisition of data, analysis data: Jiali Ma, Qinglin Yu, Taomei Zhang; Drafting and writing of manuscript: Ying Zhang, Jiali Ma; Revised, reviewed and approved the manuscript: Ying Zhang, Jiali Ma, Qinglin Yu, Taomei Zhang.

Conflicts of interest

The authors have declared that no conflicts of interest exist.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ijnss.2019.11.005.

References

[1] Manners PJ, Bower C. Worldwide prevalence of juvenile arthritis why does it vary so much? J Rheumatol 2002;29(7):1520–30. https://doi.org/10.1097/01.BOR.0000017627.98683.8D.
[2] Kamphuis S, Silverman ED. Prevalence and burden of pediatric-onset systemic lupus erythematosus. Nat Rev Rheumatol 2010;6(9):538–46. https://doi.org/10.1038/nrrheum.2010.121.
[3] Consolaro A, Giancane G, Alongi A, van Dijkhuizen E, Aggarwal A, Al-Mayouf SM, et al. Phenotypic variability and disparities in treatment and outcomes of childhood arthritis throughout the world: an observational cohort study. Lancet Child Adolesc Health 2019;3(4):255–63. https://doi.org/10.1016/S2352-4642(19)30027-6.
[4] Kahn PJ. Juvenile idiopathic arthritis - what the clinician needs to know. Bull Hosp Jt Dis 2013;71(3):194–9.
[5] Stinson JN, Connelly M, Jibb LA, Schanberg LE, Walco G, Spiegel LR, et al. Developing a standardized approach to the assessment of pain in children and youth presenting to pediatric rheumatology providers: a Delphi survey and consensus conference process followed by feasibility testing. Pediatr Rheumatol Online J 2012;10(1):7. https://doi.org/10.1186/1546-0096-10-7.
[6] Moorthy LN, Peterson MG, Hassett A, Baratelli M, Lehman TJ. Impact of lupus on school attendance and performance. Lupus 2010;19(5):620–7. https://doi.org/10.1177/0961203309355810.
[7] LeBovidge JS, Lavigne JV, Donenberg GR, Miller ML. Psychological adjustment of children and adolescents with chronic arthritis: a meta-analytic review. J Pediatr Psychol 2003;28(1):29–39. https://doi.org/10.1093/jpepsy/28.1.29.
[8] O'Sullivan P, Beales D, Jensen L, Murray K, Myers T. Characteristics of chronic non-specific musculoskeletal pain in children and adolescents attending a rheumatology outpatients clinic: a cross-sectional study. Pediatr Rheumatol Online J 2011;9(1):3. https://doi.org/10.1186/1546-0096-9-3.
[9] Hyrich KL, Lal SD, Foster HE, Thornton J, Adib N, Baildam E, et al. Disease activity and disability in children with juvenile idiopathic arthritis one year following presentation to paediatric rheumatology. Results from the Childhood Arthritis Prospective Study. Rheumatology (Oxford) 2010;49(1):116–22. https://doi.org/10.1093/rheumatology/kep352.
[10] Rasu RS, Cline SK, Shaw JW, Hayes O, Agbor BW, Cifaldi MA. Impact of JIA on parents' work absences. Rheumatology (Oxford) 2015;54(7):1177–85. https://doi.org/10.1093/rheumatology/keu414.
[11] Romley JA, Shah AK, Chung PJ, Elliott MN, Vestal KD, Schuster MA. Family-provided health care for children with special health care needs. Pediatrics 2017;139(1):e20161287. https://doi.org/10.1542/peds.2016-1287.
[12] Li R, Xiong F, Hu YJ, Hou L, Cheng XR, Luo YH, et al. Survey and analysis of quality of life in children and adolescents with type 1 diabetes. J Zhejiang Univ (Medical Science) 2013;42(4):388–95. https://doi.org/10.3785/j.issn.1008-9292.2013.04.004 [in Chinese)].
[13] Ramos RM, Nobrega V, Fernandes L, Machado AN, Collet N. Paternal care to children and adolescent with chronic disease: maternal perception. Rev Gaucha Enferm 2018;38(3):e6. https://doi.org/10.1590/1983-1447.2017.03.2016-0006.
[14] Grande SW, Longacre MR, Palmblad K, Montan MV, Berquist RP, Hager A, et al. Empowering young people living with juvenile idiopathic arthritis to better communicate with families and care teams: content analysis of semi-structured interviews. JMIR Mhealth Uhealth 2019;7(2). https://doi.org/10.2196/10401. e10401.
[15] Ramelet AS, Fonjallaz B, Rio L, Zoni S, Ballabeni P, Rapin J, et al. Impact of a nurse led telephone intervention on satisfaction and health outcomes of children with inflammatory rheumatic diseases and their families: a crossover randomized clinical trial. BMC Pediatr 2017;17(1):168. https://doi.org/10.1186/s12887-017-0926-5.
[16] Yuwen W, Lewis FM, Walker AJ, Ward TM. Struggling in the dark to help my child: parents' experience in caring for a young child with juvenile idiopathic arthritis. J Pediatr Nurs 2017;37:e23–9. https://doi.org/10.1016/j.pedn.2017.07.007.
[17] Kim DH, Im YJ. The influence of family management style on psychosocial problems of childhood cancer survivors in Korea. Eur J Oncol Nurs 2015;19(2):107–12. https://doi.org/10.1016/j.ejon.2014.10.010.
[18] Beacham BL, Deatrick JA. Adapting the family management styles framework to include children. J Pediatr Nurs 2019;45:26–36. https://doi.org/10.1016/j.pedn.2018.12.006.
[19] Ergun A, Sisman FN, Erol S, Gur K, Kolac N, Kadioglu H. The family management of childhood chronic conditions: measurement in a Turkish sample. J Pediatr Nurs 2019;47:e16–23. https://doi.org/10.1016/j.pedn.2019.04.008.
[20] Knafl KA, Deatrick JA, Havill NL. Continued development of the family management style framework. J Fam Nurs 2012;18(1):11–34. https://doi.org/10.1177/1074840711427294.
[21] Knafl K, Deatrick JA, Gallo A, Dixon J, Grey M, Knafl G, et al. Assessment of the psychometric properties of the family management measure. J Pediatr Psychol 2011;36(5):494–505. https://doi.org/10.1093/jpepsy/jsp034.
[22] Ravelli A, Martini A. Juvenile idiopathic arthritis. Lancet 2007;369(9563):767–78. https://doi.org/10.1016/S0140-6736(07)60363-8.
[23] Thong B, Olsen NJ. Systemic lupus erythematosus diagnosis and management. Rheumatology (Oxford) 2017;56(suppl_1):i3–13. https://doi.org/10.1093/rheumatology/kew401.
[24] Giancane G, Alongi A, Rosina S, Tibaldi J, Consolaro A, Ravelli A. Recent therapeutic advances in juvenile idiopathic arthritis. Best Pract Res Clin Rheumatol 2017;31(4):476–87. https://doi.org/10.1016/j.berh.2018.01.001.
[25] Thakral A, Klein-Gitelman MS. An update on treatment and management of pediatric systemic lupus erythematosus. Rheumatol Ther 2016;3(2):209–19. https://doi.org/10.1007/s40744-016-0044-0.
[26] Phillippi K, Hoeltzel M, Byun RA, Kim S. Race, income, and disease outcomes in juvenile dermatomyositis. J Pediatr 2017;184(1):38–44. https://doi.org/10.1016/j.jpeds.2017.01.046.
[27] Drozek D, Diehl H, Nakazawa M, Kostohryz T, Morton D, Shubrook JH. Short-term effectiveness of a lifestyle intervention program for reducing selected chronic disease risk factors in individuals living in rural appalachia: a pilot cohort study. Adv Prev Med 2014;2014(1):798184. https://doi.org/10.1155/2014/798184.
[28] Didsbury MS, Kim S, Medway MM, Tong A, McTaggart SJ, Walker AM, et al. Socio-economic status and quality of life in children with chronic disease: a systematic review. J Paediatr Child Health 2016;52(12):1062–9. https://doi.org/10.1111/jpc.13407.
[29] Xiong J. Analysis of prognostic factors in children with systemic lupus erythematosus. J Clin Medicat Pract 2015;19(11):176–7. https://doi.org/10.7619/jcmp.201511065 [in Chinese)].
[30] Tang XM, Zhao XD, Yang XQ. Pay attention to the progress in pediatric rheumatic diseases in China. Zhonghua Er Ke Za Zhi 2011;49(7):481–4. https://doi.org/10.3760/cma.j.issn.0578-1310.2011.07.001 [in Chinese)].
[31] World Health Organization (WHO). Investing in noncommunicable disease control generates major financial and health gains. Available at: https://www.who.int/news-room/detail/16-05-2018-investing-in-noncommunicable-disease-control-generates-major-financial-and-health-gains; 2018.
[32] Zhang Y, Wei M, Zhang YQ, Shen NP. Impact of family management on family functioning of families with chronically ill children. J Shanghai Jiaot Univ (Medical Science) 2013;33(5):531–7. https://doi.org/10.3969/j.issn.1674-8115.2013.05.002 [in Chinese)].
[33] Sheng N. The association among family management, transition readiness and quality of life of children with chronic diseases. Shanghai Jiao Tong University; 2018 [in Chinese)].
[34] Zhang Y, Wei M. Validity and reliability of the Chinese version of family management measure. Chin J Pract Nurs 2009;25(5):19–22. https://doi.org/10.3969/j.issn.1674-8115.2013.05.002 [in Chinese)].
[35] U.S. Bureau of Labor Statistics. Labor force statistics from the current population survey. Available at: https://www.bls.gov/cps/cpsaat18.htm; 2018.
[36] Brown N, Gallagher R, Fowler C, Wales S. The role of parents in managing asthma in middle childhood: an important consideration in chronic care. Collegian 2010;17(2):71–6. https://doi.org/10.1016/j.colegn.2010.04.006.
[37] Knafl KA, Deatrick JA, Knafl GJ, Gallo AM, Grey M, Dixon J. Patterns of family management of childhood chronic conditions and their relationship to child and family functioning. J Pediatr Nurs 2013;28(6):523–35. https://doi.org/10.1016/j.pedn.2013.03.006.
[38] Sheng N, Ma JL, Ding WW, Zhang Y. Cluster analysis for family management of Chinese children with chronic kidney diseases. J Health Psychol 2017:1571619786. https://doi.org/10.1177/1359105317733322.
[39] Tong A, Jones J, Craig JC, Singh-Grewal D. Children's experiences of living with juvenile idiopathic arthritis: a thematic synthesis of qualitative studies. Arthritis Care Res (Hoboken) 2012;64(9):1392–404. https://doi.org/10.1002/acr.21695.
[40] Uzuner S, Sahin S, Durcan G, Adrovic A, Barut K, Kilicoglu AG, et al. The impact of peer victimization and psychological symptoms on quality of life in children and adolescents with systemic lupus erythematosus. Clin Rheumatol 2017;36(6):1297–304. https://doi.org/10.1007/s10067-017-3650-5.
[41] Leeman J, Crandell JL, Lee A, Bai J, Sandelowski M, Knafl K. Family functioning and the well-being of children with chronic conditions: a meta-analysis. Res Nurs Health 2016;39(4):229–43. https://doi.org/10.1002/nur.21725.
[42] Sullivan-Bolyai S. Facilitating family-rich outcomes for families with children who have special health care needs. J Fam Nurs 2017;23(2):167–74. https://doi.org/10.1177/1074840717697309.
[43] Huber AM, Ward LM. The impact of underlying disease on fracture risk and bone mineral density in children with rheumatic disorders: a review of current literature. Semin Arthritis Rheum 2016;46(1):49–63. https://doi.org/10.1016/j.semarthrit.2016.02.003.
[44] Chausset A, Gominon AL, Montmaneix N, Echaubard S, Guillaume-Czitrom S, Cambon B, et al. Why we need a process on breaking news of Juvenile Idiopathic Arthritis: a mixed methods study. Pediatr Rheumatol Online J

2016;14(1):31. https://doi.org/10.1186/s12969-016-0092-6.
[45] Prakken B, Albani S, Martini A. Juvenile idiopathic arthritis. Lancet 2011;377(9783):2138–49. https://doi.org/10.1016/S0140-6736(11)60244-4.
[46] Harry O, Yasin S, Brunner H. Childhood-Onset systemic lupus erythematosus: a review and update. J Pediatr 2018;196:22–30. https://doi.org/10.1016/j.jpeds.2018.01.045.
[47] Sheng N, Ma JL, Ding WW, Zhang Y. Family management affecting transition readiness and quality of life of Chinese children and young people with chronic diseases. J Child Health Care 2018;22(3):470–85. https://doi.org/10.1177/1367493517753712.
[48] Greenaway ES, Leon J, Baker DP. Understanding the association between maternal education and use of health services in Ghana: exploring the role of health knowledge. J Biosoc Sci 2012;44(6):733–47. https://doi.org/10.1017/S0021932012000041.
[49] Lewis KA, Brown SA, Tiziani S, Carrasco R. Sociocultural considerations in juvenile arthritis: a review. J Pediatr Nurs 2017;37:13–21. https://doi.org/10.1016/j.pedn.2017.08.023.
[50] Swindle TM, Shapley K, Kyzer A, Cheerla R, Whiteside-Mansell L. Familial risk in low-income children with chronic illness exposed to passive smoke. Clin Pediatr (Phila) 2015;54(9):840–6. https://doi.org/10.1177/0009922815589927.